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Social stigma and the quality of life among patients with schizophrenia

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Abstract

Background: Schizophrenia is a mental illness or disorder experienced by most people in the world. The stigma that exists in society with mental disorders is very high, where family acceptance and family support are shown through attitudes, actions that will greatly affect the quality of life of schizophrenics.
Purpose: To find out the relationship between community stigma, family acceptance and support with the quality of life of schizophrenics.
Method: Using a descriptive cross-sectional correlation approach. The sample in this research is as many as 329 families at the Jambi Regional Mental Hospital polyclinic using purposive sampling technique. The questionnaire used was the Schizophrenia Quality Of Life Scale (SQOLS), The Devaluation Families Scale (DCFS), family acceptance and support. The analysis used is multiple linear regression.
Results: The average age of the respondents was 35.99, ranging from 17 to 70 years. recurrence of schizophrenics 1 time per year and less than 5 years of care.
Conclusion: There is a relationship between community stigma, family acceptance and support with the quality of life of schizophrenics with a p-value of 0.000 (<0.05). The dominant factor related to quality of life is family acceptance (OR = 0.534).
Suggestion: It is hoped that in caring for schizophrenics the family can be involved as a caregiver as a support system.

Keywords: Social Stigma; Quality of Life; Schizophrenia

INTRODUCTION

Schizophrenia is a mental disorder which is a major problem in developing countries. People with schizophrenia are ranked fourth in the world which are multifactorial in nature which can lead to disruption of thought patterns, thought content and cause chaos in the process of perception and behavior of each individual in social functions so that it affects the quality of life of schizophrenics itself and has a standard of living significantly worse than anyone else. Quality of life as an indicator includes several things including, physical health, psychosocial, level of dependence, individual beliefs and relationships with the surrounding environment manifested in the spirit of obtaining a source of income, self-care and independence (Karame, Legi, & Hamenda, 2018; Wardani & Dewi , 2018; Smith & Silva, 2011; Pribadi, Lin, Chen, Lee, Fitryasari, & Chen, 2020).

Based on several studies of schizophrenics having a low quality of life, this is known from the results of research which states that the quality of life of schizophrenics is in a low classification including quality of life in general and the environment, namely 66.92 (SD = 11.60) (Hayhurst, Massie, Dunn, Lewis, & Drake, 2014; Wardani & Dewi, 2018). Another study in Nigeria found that the average quality of life for ODS was

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low, namely 76.19 (SD=10.34) (Adelufosi, Ogunwale, Abayomi, & Mosanya, 2013). The impact on quality of life and having a standard of living that is significantly worse than other people includes several things including, physical health, mental health, level of dependence, individual beliefs and relationships with the surrounding environment (Afconneri & Puspita, 2020).

Families are two or more individuals who are joined together to share experiences and take emotional approaches and make themselves part of the family (Wulandari & Fitriani, 2020; Adristi, 2021; Pardede, 2022). Problems that arise in family acceptance related to schizophrenics conditions are a lot of time wasted at work and a lot of living expenses and limited time to socialize so that feelings of stress, depression, shame, guilt and stigma arise from the family (Rahman & Permana, 2020).

The phenomenon that occurs is that support from the family will affect the quality of life of schizophrenics, where quality of life is associated with life satisfaction, happiness, morale and health related to functional abilities thereby reducing recurrence in schizophrenics. Preliminary studies at the outpatient service unit of the Jambi provincial mental hospital, the efforts made by the hospital include instructing each schizophrenics to take control of treatment to the Jambi Province Regional Psychiatric Hospital. There were several schizophrenics families who were interviewed 6 out of 10 families said schizophrenics looked hopeless, families said they often saw schizophrenics panic, families said schizophrenics looked difficult to concentrate, families said schizophrenics looked restless, 6 out of 10 schizophrenics families said they were embarrassed by family members who had disorders , the family said schizophrenics was angry when asked about their past and the family said schizophrenics seemed to feel uncomfortable with other people who always considered them sick.

METHOD

The type of research used is quantitative, descriptive correlation which explains or looks for a relationship, estimates and tests based on existing theory. The research design used is a cross-sectional study. Measurements in this study were carried out only once using a questionnaire to respondents to obtain data simultaneously without any follow-up.

The population in this study were schizophrenics who were outpatient at the Jambi Province Regional Psychiatric Hospital polyclinic and living with their families, who controlled treatment in January 2023 as many as 1,191 people (The Regional Mental Hospital of Jambi Province, 2023). The sample in this study was included in the inclusion criteria that had been set by the researcher so as not to deviate, with the inclusion criteria of families who accompanied schizophrenics to control treatment, schizophrenics families who lived together and cared for schizophrenics, schizophrenics families who could read and write and could understand the meaning stated on the questionnaire, schizophrenics families who are ≥ 20 years old and schizophrenics families who are willing to be respondents and are willing to fill out the questionnaire. And the exclusion criteria were schizophrenics families who had conditions or diseases that interfered with the measurement and interpretation of results, stroke/dimensia which made it impossible to become respondents, and a sample of 329 respondents was obtained.

Measuring the quality of life of schizophrenics uses the Schizophrenia Quality Of Life Scales (SQOL), the SQOLS contains 29 question items belonging to three domains: psychosocial feelings (19 items), motivation and energy (2 items) and the domain of symptoms of treatment effects (8 items). Scores on a 5-point Likert-type scale (1 = never, 2 = rarely, 3 = sometimes, 4 = often, 5 = always) low values indicate a relatively poor quality of life. All questionnaires were assessed using a likert scale format. Each question is added with the lowest score of 29 and the highest score of 145 (Su, Yang, & Lin, 2017). To interpret the categorization, it is given a value from the results of the mean formula (Low = X<M -1SD, Moderate = M -1 SD≤ X <M -1 SD, High = M +1SD≤ X) and standard deviation of quality of life with 3 categories, low = < 60, moderate = 60 - 107 and high = > 107 (Azwar, 2012).

The Devaluation Families Scale (DCFS) questionnaire is an instrument for measuring

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community perceptions/stigma against family members of schizophrenics. There are 3 factors from DCFS that are combined to assess the perception/stigma that is felt towards family members of schizophrenics, namely community rejection (6 items), causal attribution (2 items) and parents not caring (1 item). This instrument uses a Likert scale with 4 points, namely strongly disagree, disagree, agree, strongly agree. In this questionnaire there are 6 questions with positive words on questions 1, 2, 5, 6, 8, with a score of 4 = strongly disagree, 3 = disagree, 2 = agree, 1 = strongly agree. Whereas 4 other question items with negative words, namely questions 3, 4, 7, 9 with a score of 1=strongly disagree, 2=disagree, 3=agree, 4=strongly agree, all questionnaires are assessed using the Likert scale format . Each question is added with the lowest score of 9 and the highest score of 36. For categorizing interpretations are given a value from the results of the mean and standard deviation formula (Low = X<M -1SD, Medium = M -1 SD≤ X < M -1 SD, High = M +1SD ≤ X) community stigma with 3 categories low = < 16, medium = 16-21 and high = >21.

Questionnaire regarding family acceptance consisting of 24 statements which have been tested valid by (Laksmi & Herdiyanto, 2019) at Psychiatric Hospital Prof. Dr. Muhammad Ildrem with a validity test value of 0.833 and reliability (r = 0.865). The score for this instrument is 4 = always, 3 = often, 2 = sometimes and 1 = never. This instrument uses 24 questions with positive words without being accompanied by questions with negative words. Giving a likert scale. Each question is added with the lowest score of 24 and the highest score of 96. For categorization interpretation, a value is given from the results of the formula for the mean and standard deviation (Low = X<M -1SD, Medium = M -1 SD≤ X < M -1 SD, High = M +1SD≤ X) family acceptance with 3 categories low = <66, medium = 66 -87 and high = >87.

The family support questionnaire used cited research (Prameswari, 2018) as many as 18 statements describing family support which included emotional support (3 questions), information support (5 questions), instrumental support (5 questions) and assessment support (5 questions). , this questionnaire uses a likert scale consisting of a value of 1 = never, value 2 = sometimes, value 3 = often and value 4 = always. Each question is added with the lowest score of 18 and the highest score of 72. For categorization interpretations are given a value from the results of the formula mean and standard deviation (Low = X< M -1SD, Moderate = M -1 SD≤ X < M -1 SD, High = M +1SD ≤ X) family support with 3 categories low = 52, medium = 52-67 and high = >67. The frequency of recurrence is categorized as low if it is 1x per year and high if it is more than once per year, and for the duration of care it is categorized as 1 < 5 years and 2 > 5 years.

Data analysis uses the Pearson product moment test. If the data results are normally distributed, if the data results are not normally distributed, then use Spearman.

This research has been declared ethically feasible by the Health Research Ethics Committee of the Faculty of Nursing, Andalas University, Padang with the number: 053.laiketik/KEPKFKEPUNAND.

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RESULTS

Table 1. Characteristics of the Respondents (N=329)

Variabel	Hasil
Age (Mean±SD)(Range)(Years)	(35.99±9.63)(17-70)
Gender (n/%)	
Man	194/58.97
Woman	135/41.03
Education (n/%)	
No Education	17/5.17
Junior High School	102/31
Senior High School	188/57.14
Post Graduated	22/6.69
Occupation (n/%)	
Works	220/66.87
Unwork	109/33.13
Marital status (n/%)	
Marry	227/69
Unmarried	71/21.58
Widower	31/9.42
Relations with Schizophrenics (n/%)	
Father	50/15.20
Mother	41/12.46
Child	66/20.06
Husband	40/12.16
Wife	23/6.99
Brother/Sister	109/33.13
Relapse Frequency (n/%)	
Low	187/56.84
High	142/43.16
Long for Care (n/%)	
< 5 Year	183/55.62
> 5 Year	146/44.38

Based on table 1 it can be seen that the mean and standard deviation of the respondents' ages are (35.99 ± 9.63) with an age range between 17 to 70 years. The majority are male as much as 58.97%, with high school education 57.14%, working 66.87%, with married status 69%, relationship status with patients is brother/sister as much as 33.13%, with low relapse frequency 56.84%, and length of care for schizophrenics < 5 years as much as 55.62%.

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Table 2. Average Quality of Life for Schizophrenics, Community Stigma, Acceptance and Family Support (N = 329)

Variable (Mean±SD)(Range)	Mean	SD	Min-Maks	95%CI
Quality of Life of Schizophrenics	84,00	23,306	30-145	81,47-86,53
Community Stigma	19,00	2,436	13-28	18,52-19,05
Family Acceptance	77,00	10,545	54-96	75,86-78,14
Family Support	60,00	7,886	45-72	59,14-60,86

Based on table 2, the average ODS quality of life is 84.00, which means that the ODS quality of life is moderate with the lowest ODS quality of life being 30 and the highest being 145 and a standard deviation of 23.306. While the average community stigma is 19.00, which means medium community stigma with the lowest community stigma 13 and the highest 28 and a standard deviation of 2.436. Average family income is 77.00, which means moderate family income with the lowest family income of 54 and the highest of 96 and a standard deviation of 10.545. The average family support is 60.00, which means that family support is moderate with the lowest family support being 45 and the highest being 72 with a standard deviation of 7.886.

Table 3. Analysis of Community Stigma, Family Acceptance and Family Support with Quality of Life of Schizophrenics

Variable	Coefficient Correlation (r)	Unstandardized B	Coefficients S.E	Exponents (B)	t	Sig
Community Stigma	-0,196	-0,610	0,100	-0,064	-6,092	0,000
Family Acceptance	0,975	1,180	0,092	0,534	13,278	0,000
Family Support	0,969	1,319	0,124	0,446	11,155	0,000
Constant		-74,425	2,794		-26,639	0,000
R (*Multiple* R)		0,983				
Adjusted R Square		0,965				
F Count		3060,478				
Sign. F		0,000				
α		0,05				

Based on the r count (person correlation) it is known that the correlation coefficient for community stigma with quality of life of schizophrenics is -0.196, the weaker the community stigma, the stronger the quality of life of schizophrenics. The correlation coefficient value for family acceptance with quality of life of schizophrenics is 0.975, the stronger the family acceptance, the stronger the quality of life of schizophrenics and the correlation coefficient value for family support with quality of life of schizophrenics is 0.969, the stronger the family support, the stronger the quality of life of schizophrenics.

In multivariate analysis multiple linear regression tests with linear line equations and obtained through 1 step of modeling and obtained the most dominant variable related to the quality of life of schizophrenics is family acceptance where p-value = 0.000 and Exponential B(OR) value = 0.534, which means where family acceptance has a chance of 0.5 times the quality of life of schizophrenics.

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DISCUSSION

Based on this analysis it shows that community stigma at the time of collecting questionnaire data with a mean value of mean (19.00) and SD (2.436). This is in line with research at the psychiatric polyclinic of a mental hospital in Jakarta which states that the average community stigma is (18.22) (Wardani & Dewi, 2018). The results of previous research stated that the average community stigma is (22.00), which means it tends to be high (Edward, Putri, & Refrandes, 2021). The results of research in Ruwolong Hamlet show that (91%) the community accepts schizophrenics well as evidenced by the results of the research that most people in Ruwolong Hamlet have a positive view of schizophrenics believing that schizophrenics is not a curse from those in power, it does not have to be isolated from the whole community, schizophrenics can be cured, families who help provide medication (Mane, Kuwa, & Sulastien, 2022). The results of a study in Vietnam also showed that family members who cared for schizophrenics felt a high level of stigma, as indicated by half (40.3%) of families with high community stigma obtained from the results of a questionnaire, some families thought that the community did not want to visit schizophrenics family members' homes. (53.9%) families think that the community will be afraid to visit the house because they care for schizophrenics family members, the community will blame the family with schizophrenics for the cause of relapse (29.7%), high community stigma in family perceptions can be related to community knowledge (Ngoc, Weiss, & Trung, 2016).

Community stigma is an attitude, view and reflection of behavior in a negative context towards someone/something that is considered inferior by society, community stigma towards schizophrenics has a negative impact on schizophrenics such as poor medication adherence, slow healing and self-isolation from the community environment (Subu, Holmes, & Elliot, 2016). According to research in India, family members as caregivers almost experience high social stigma, this gives an uncomfortable feeling for family members to care for schizophrenics and there are still family members who care for schizophrenics who do not want to tell the status of schizophrenics family members (Koschorke, Padmavati, Kumar , Cohen, Weiss, Chatterjee, & Thornicroft, 2017).

According to the analysis, the researchers explained that the community's stigma still influenced most of the people around the home environment so that family members prioritized schizophrenics care and were consistent in providing time to provide care to schizophrenics. This is proved after the analysis of the questionnaire.

CONCLUSION

The weaker the community stigma, the stronger the quality of life of schizophrenics, the stronger the family's acceptance, the stronger the quality of life of schizophrenics and the stronger the family support, the stronger the quality of life of schizophrenics.

There is a significant relationship between community stigma, family acceptance and support on the quality of life of schizophrenics.

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